Complete Summary

GUIDELINE TITLE

The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children.

BIBLIOGRAPHIC SOURCE(S)

American Academy of Pediatrics: The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. Pediatrics 2001 May; 107(5):1221-6. [70 references]

GUIDELINE STATUS

This is the current release of the guideline.

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INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IDENTIFYING INFORMATION AND AVAILABILITY DISCLAIMER

SCOPE

DISEASE/CONDITION(S)

Autistic spectrum disorder (ASD) (also known as "autism"), encompasses the classic autistic order and other pervasive development disorders. (Note: The guideline focuses on autistic disorder and its milder variants, including Asperger syndrome and pervasive developmental disorder - not otherwise specified [PDD-NOS].)

GUIDELINE CATEGORY

Diagnosis Evaluation Management

CLINICAL SPECIALTY

Family Practice Neurology Pediatrics

INTENDED USERS

Physicians

GUIDELINE OBJECTIVE(S)

To help the pediatrician recognize the early symptoms of autism and participate in its diagnosis and management

TARGET POPULATION

Infants and children with suspected or confirmed autistic spectrum disorder (autism)

INTERVENTIONS AND PRACTICES CONSIDERED

Diagnosis and Evaluation

- 1. Screening and surveillance, including evaluation of social-emotional milestones and traditional motor, cognitive, and language skills
- 2. Use of Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV criteria for autistic spectrum disorder, Checklist for Autism in Toddlers (CHAT), and Pervasive Developmental Disorder Screening Test (PDDST)
- 3. Use of standardized assessment tools for autistic spectrum disorder, including the Childhood Autism Rating Scale (CARS), the Autism Behavior Checklist (ABC), the Gilliam Autism Rating Scale, the Autism Diagnostic Interview-Revised (ADI-R), and the Autism Diagnostic Observation Schedule (ADOS)
- 4. Physical examination for the presence of dysmorphic features, such as, macrocephaly posterior rotated ears, long face, large ears, and large testes (postpubertally)
- 5. Examination of the skin with a Wood's light
- 6. Comprehensive speech and language and audiologic evaluations
- 7. Genetic screening for Fragile X and phenylketonuria
- 8. Electroencephalogram for the evaluation of seizures, when necessary
- 9. Magnetic resonance imaging (MRI) to evaluate children with autistic spectrum disorder who also have dysmorphic features or localizing neurologic signs

Management

1. Support for parents and families, including method of presenting initial diagnosis, education, counseling, support groups, genetic counseling prior to

- conception of subsequent siblings, and referrals for social services and other professionals
- 2. Early developmental interventions, including enrollment in a program with a curriculum that aims to improve overall functional and behavioral status
- 3. Provision of additional therapies, including behavior management, speech therapy, augmentative communication methods, occupational therapy, physical therapy, extensive parent training, community support, and development of positive social relationships
- 4. Educational interventions for school aged children that provide structure, direction, and organization and are individualized to the child
- 5. Medical management activities, such as health promotion and disease prevention as provided to children without disabilities
- 6. Medications, such as neuroleptics (haloperidol, thioridazine, risperidone); selective serotonin reuptake inhibitors; stimulants; clonidine hydrochloride; guanfacine hydrochloride; lithium; melatonin; and anticonvulsants (carbamazepine, valproic acid)
- 7. Evaluation for psychopathologic problems, such as mood disorder, anxiety disorders, attention deficit/hyperactivity disorder, and obsessive-compulsive disorder
- 8. Discussion of alternative therapies, such as nutritional supplements, elimination diets, immune globulin therapy, secretin, chelation therapy, auditory integration therapy, and facilitated communication

MAJOR OUTCOMES CONSIDERED

- Scores on screening tools such as the Checklist for Autism in Toddlers (CHAT) and the Pervasive Developmental Disorder Screening Test (PDDST)
- Scores on comprehensive standardized assessment tools, such as, the Childhood Autism Rating Scale (CARS), the Autism Behavior Checklist (ABC), the Gilliam Autism Rating Scale, and the Autism Diagnostic Interview-Revised (ADI-R)
- Intellectual and behavioral functioning

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Not stated

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Not stated

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not stated

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

- 1. Pediatricians should listen carefully to parents when discussing their child's development. They are reliable sources of information, and their concerns should be valued and addressed immediately.
- 2. In the context of the medical home, pediatricians should monitor all areas of development at each well-child visit. They should be especially vigilant when there are deficits in language and social skill development.
- 3. Pediatricians should consider using screening and diagnostic tools specific for autistic spectrum disorder. Such tools should be ethnoculturally and linguistically appropriate. If a pediatrician feels unable to do so, the child should be promptly referred to a specialist or, preferably, a multidisciplinary team of specialists with expertise in autistic spectrum disorder.
- 4. Any child who has language delays should be referred for an audiologic and a comprehensive speech and language evaluation. If the child is uncooperative,

- diagnostic otoacoustic emissions or sedated brainstem auditory evoked responses should be obtained.
- 5. Pediatricians should continue to promote immunizations for all children. Continued high immunization rates are crucial in preventing an increase in life-threatening infectious diseases. Parents should be reassured that at the present time, there is no scientific evidence to support claims that the measles-mumps-rubella (MMR) vaccine or any combination of vaccines cause autistic spectrum disorder. A decision to not vaccinate places children and communities at risk.
- 6. Lead screening is indicated in the presence of risk factors, particularly pica, even in an older child. DNA analysis, high-resolution chromosome analysis, and referral to a geneticist should be considered in the presence of dysmorphic features, family history of fragile X syndrome, or mental retardation of undetermined etiology. (Filipek et al., 1999; Filipek et al., 2000) Electroencephalography and a neurology referral are indicated in children with suspected seizures or those who have symptoms of regression. Decisions to pursue additional investigation (e.g., neuroimaging) or consultation for a coexisting etiologic diagnosis (e.g., phenylketonuria, tuberous sclerosis, etc.) should be made on the basis of the history and physical examination, including an assessment for focal neurologic signs. (Filipek et al., 1999; Filipek et al., 2000)
- 7. Once the diagnosis of autistic spectrum disorder is made, the family and caregivers should be provided with current literature and information regarding parent support groups, specific autism intervention programs, and other available community services.
- 8. Families should receive genetic counseling appropriate to the etiologic diagnosis. Parents of a child with apparently isolated autistic spectrum disorder should be counseled regarding the increased recurrence risk (3%-7%) in subsequent children. When following a younger sibling of a child with known autistic spectrum disorder, pediatricians should demonstrate a high level of vigilance and monitor the child closely for any developmental or behavioral concern.
- 9. Any child with a suspected delay or symptoms of autistic spectrum disorder should be given the opportunity to enroll in an age-appropriate early intervention program or school program immediately, even before a definitive diagnosis is available. Because these programs are federally mandated (Individuals With Disabilities Education Act. Pub L No. 94-142, 1990; Individuals With Disabilities Education Act. Pub L No. 105-17, 1997) (and fully implemented in most states), children with delayed or deviant development are entitled to them. Although criteria may vary slightly among states, eligibility for these programs is based on the presence of a delay, not on a categoric diagnosis.
- 10. Because many parents of children with autistic spectrum disorder pursue alternative therapies, pediatricians are encouraged to become familiar with the more popular ones and approach the issue objectively and compassionately. (Nickel, 1996; Hyman & Levy, 2000)
- 11. Pediatricians should provide comprehensive care of the child with autistic spectrum disorder in the context of a medical home. This includes provision of medical interventions and coordination of care with appropriate educational, rehabilitation, social, and subspecialty pediatric services.
- 12. In the event of an untimely death, physicians should encourage parents of a child with autistic spectrum disorder to consent to tissue donation to support autistic spectrum disorder research endeavors. To advance this effort,

national autism organizations have established a centralized brain bank. For more information, one may call: 1-800-BRAIN-BANK.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

REFERENCES SUPPORTING THE RECOMMENDATIONS

References open in a new window

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting each recommendation is not specifically stated.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Increasing the pediatrician's knowledge and comfort level of caring for children with autism may lead to earlier diagnosis and referral for appropriate interventions, which will, in turn, have a positive effect on long-term outcomes for children with autism and their families.

POTENTIAL HARMS

Adverse effects of medications used in treatment of symptoms of autistic spectrum disorder include the following:

- Older neuroleptics, such as haloperidol and thioridazine. Their usefulness is limited by sedation, irritability, and extrapyramidal dyskinesias.
- Risperidone. It has fewer extrapyramidal adverse effects than haloperidol and thioridazine; however, most children experience a fairly significant weight gain within the first few months of treatment.
- Selective serotonin reuptake inhibitors. Adverse effects are uncommon but include restlessness, hyperactivity, agitation, and insomnia.
- Stimulants. Stimulant therapy may actually increase aggressiveness and stereotypical behavior.

QUALIFYING STATEMENTS

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The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

Implementation of the strategies in the guideline depends on educating and empowering pediatricians to recognize the wide spectrum of symptoms that autistic spectrum disorder now comprises and use standardized developmental and autistic spectrum disorder-specific screening and diagnostic tools. Implementation also depends on reimbursement policies that allow additional well-child visits during toddler and preschool years and adequate time to use these tools. Reimbursement mechanisms must take into account efforts needed to provide comprehensive management and coordination of care in the context of the medical home.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

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ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2001 May

GUIDELINE DEVELOPER(S)

American Academy of Pediatrics - Medical Specialty Society

SOURCE(S) OF FUNDING

American Academy of Pediatrics

GUIDELINE COMMITTEE

Committee on Children With Disabilities

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

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GUIDELINE AVAILABILITY

Electronic copies: Available from the <u>American Academy of Pediatrics (AAP) Policy</u> Web site.

Print copies: Available from AAP, 141 Northwest Point Blvd., P.O. Box 927, Elk Grove Village, IL 60009-0927.

AVAILABILITY OF COMPANION DOCUMENTS

The following is available:

• American Academy of Pediatrics, Committee on Children with Disabilities. Technical report: the pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. Pediatrics 2001 May; 107(5):e85.

Electronic copies: Available from the <u>American Academy of Pediatrics (AAP) Policy</u> Web site.

Print copies: Available from AAP, 141 Northwest Point Blvd., P.O. Box 927, Elk Grove Village, IL 60009-0927.

PATIENT RESOURCES

None available

NGC STATUS

This summary was completed by ECRI on October 17, 2001. The information was verified by the guideline developer as of December 5, 2001.

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